

# Alzheimer's and Related Disorders Society of India

ARDSI- Bangalore Chapter



## Annual Report 2015-16

### **Introduction:**

The Alzheimer's and Related Disorders Society of India is a registered non-profit organization dedicated to care, training and research in dementia. It has 21 chapters across the country.

The ARDSI -Bangalore Chapter registered in 2006, strives to generate necessary awareness and create appropriate support systems for persons with dementia and caregivers in collaboration with governmental agencies, voluntary organizations and care professionals through support groups meetings, training, rehabilitation, awareness and advocacy and other need based programs for the well-being and better quality of life of the elderly and the family carers providing care and support.

The year 2015-16, has been a year of initiatives and involvement from our enthusiastic family carers and volunteers.

### **New members:**

During the year 2015-16, 52 persons have become life members and 15 took annual membership.

We have a total of 168 members who have joined us through the support groups, World Alzheimer's day 2015, committee members and well-wishers.

## **Awareness and memory screening:**



Regular public education programs focusing on healthy ageing and dementia were organized for senior citizens forums in Coles Park and Vidyaranyapura, students from humanitarian and social science departments and volunteers. We have been able to reach out to atleast 200 people through these programs.

Memory screening was done for 18 individuals using ACE-R, out of which one was referred for further assessment. Almost 45 elders were also screened and made aware of what it means to have memory problems. Through these programs, we have also been able to educate public regarding the activities and services rendered by the Bangalore Chapter of ARDSI.

## **World Alzheimer's day 2015**

Alzheimer's and Related Disorders Society of India (ARDSI), Bangalore Chapter organized a Reverse Walk on 20th September, 2015 at Freedom Park, Bangalore in association with Nightingales Centre for Ageing and Alzheimer's (NCAA) and National Institute for Mental Health and Neurosciences (NIMHANS). Over 500 persons participated in this event.



The event was graced by the presence of dignitaries including Dr. P.Satish Chandra, Director, NIMHANS, Mr. JavagalSrinath and Mr. Venkatesh Prasad (former cricketers); and cine actors, Mrs. AnuPrabhakar, Mr. Prem, Ms. Shruthi, Mr. Rakshith and Mr. Hemanth. We also had family care givers, large group of elders and young adults, medical and para medical staff from various institutions and volunteers. People from different walks of life had gathered together to draw the attention of the policy makers and the community to the urgent need for setting up appropriate care facilities to support people with dementia in Karnataka.



The theme for this year was **REMEMBER ME**. Walking down the memory lane, symbolizing the sweet memories of their loved ones with dementia, Mr.JavagalSrinath along with the family carers, raised balloons with the names of the person with dementia. We also took this opportunity to honor police personnel's who have helped re-unite elders to their families.

This event was also an opportunity to launch our new initiative that aims at subsidizing the cost of dementia care.

### **Subsidized Dementia Care Program**

Dementia is a neuro generative disorder with serious implication on the person and the family. In a society that still lacks awareness largely, the burden is on the immediate family. With the disease comes a host of other issues and one such issue is the increasing direct and indirect cost of care.

Keeping this in mind, our Chapter initiated the comprehensive dementia care program which supports the socio economically disadvantaged elders through subsidizing the cost of medicines, diapers, day care and respite care. This project was initiated in March 2016, and three elders have already received financial assistance. We plan to extend the services to hospitals, Geriatric clinics across Bangalore and maximize our reach to benefit more needy elders.

### **Support Group meetings:**

Topic	Facilitator	Venue	Date	Time
Medical issues in dementia	Dr.Radha.S.Murthy	Nightingales Sandhya Kirana, Richmond town	30.05.2015	10.30 am
Behavioral and psychological symptoms in dementia	Dr.Sivakumar.P.T	Nightingales Sandhya Kirana, Richmond town	25.05.2015	10.30 am
Dementia overview	Dr.Rathnavalli	AnnaswamyMudaliar general hospital,	25.09.2015	5.00 pm

		Fraser town		
Yoga for healthy ageing	Dr.Shamanthakamani&Mrs.Chandrakala	Nightingales Bagchicentre for active ageing, JP nagar	29.11.2015	2.30 pm
Healthy eating : a lifelong approach and diet in dementia	Mrs.UmaTrasi	Nightingales elders enrichment centre, Malleshwaram	27.02.2016	2.30pm



This year, we were able to organize five Support group meetings. On an average around 20-25 caregivers have attended and benefitted from the topics dealt with. The topics are mostly decided by the caregivers through feedback forms. One of the meetings witnessed almost 40 participants.

The Support Group meeting helped bring in carers together and with this bloomed a small whatsapp group. Now we have 14 family carers who support each other and share a bonding.

## **Staying Connected.....**

ARDSI Bangalore Chapter is active on social media platforms. Event details and photographs are posted regularly. With the launch of our website, Facebook /twitter account, our presence is felt in the digital world. We also network with various like-minded people and voluntary organizations across the country to support people with dementia and their carers, spread awareness and advocate for this cause.

## **Events:**

### ARDSI National conference



The ARDSI National conference was held at Mumbai on 3rd and 4th December.

Dr.Radha.S.Murthy, president of ARDSI Bangalore Chapter and Mrs.Anupama Suresh, committee member and a family carer; represented the ARDSI Bangalore chapter.

### CSR: Awareness event:

ARDSI-Bangalore Chapter was invited by Texas instrument to put up a stall at their organization, to bring in more awareness about our Chapter's activities and volunteering opportunities. Around 12 to 15 employees visited our stall.

## Dementia helpline

Telephonic counseling, guidance and support are given to family carers and individuals regarding locally available services and support for the person with dementia. The two dementia helplines: 9379792906 / 9379830631, functions on all working days between 9 am and 9 pm. Caregiving members and professionals from across the country reach out to us with various queries related to dementia care, training, careers, support services available locally. Publicity of our helpline numbers is done through ARDSI websites, brochures, awareness material, and NMT vehicle.



Home Care	11
Residential care	11
Day care	8
Information on the disease	4
Training	2
Consultation	10
Others(job, old age homes, careers etc)	14
<b>Total calls received in 2015-16</b>	<b>60</b>

Press Clippings:

THE HINDU • MONDAY, SEPTEMBER 21, 2015

### To help them remember

Ahead of World Alzheimer's Day, various organisations undertook awareness programmes in Bengaluru on Sunday. The Alzheimer's and Related Disorders Society of India - Bengaluru chapter conducted a 'Reverse Walk' to highlight the plight of those suffering from the disease. The society will present a memorandum to the government next week highlighting its demands, which include a memory clinic and other facilities for dementia patients in each district. —PHOTOS BY SUDHAKANA JAIN

THE HINDU • SUNDAY, SEPTEMBER 20, 2015

### Use it or lose it, say doctors

September 21 is World Alzheimer's Day

When a 45-year-old government employee exhibited behavioural changes, including apathy and impassiveness to emotions, his family mistook it to be depression. They suspected there was something more to it only when he developed memory loss after almost three years. Subsequently it was diagnosed as Alzheimer's by doctors at NIMHANS.

#### GENERAL SYMPTOMS

- Memory loss
- Difficulty in performing familiar tasks
- Not recognising close relatives and friends
- Difficulty in walking
- Misplacing things and blaming others

#### DOOS AND DON'TS

Doctors say early diagnosis helps in delaying progression. Apart from physical exercise, brain health exercises such as solving puzzles, reading and writing will help. People with greater mental agility and activity are at lower risk of acquiring the disease.

Doctors, who say that Alzheimer's is not just a disease of old age, point out that younger-onset Alzheimer's can affect people in their productive age as early as in the age of 40s. The best way to delay the onset of the disease is to follow a disciplined lifestyle that includes exercise, yoga, low-cholesterol and high-fibre diet and engaging in cognitive activities and social events, they say.

P.T. Sivakumar, additional professor of Psychiatry and consultant in Adult and Geriatric Psychiatry at NIMHANS, says it is challenging to diagnose younger-onset Alzheimer's as health care providers tend to generally attribute symptoms to stress or other mental illness. "The disease affects each person differently and symptoms vary. Any behavioural change after the age of 40 to 45 should not be ignored," he says.

Often confused with the normal ageing process, Alzheimer's is a form of dementia that is characterised by deterioration of the brain's functioning, he says.

Sowmya Hegde, consultant geriatric psychiatrist, at Nightingales Centre for Ageing and Alzheimer's, says tackling the disease in younger-onset patients is different from that in elders, both medically and physically. "In early-onset, the patients are young and more aggressive. Management of such cases is really challenging," she says.

Awareness levels about this condition and its symptoms are low, and facilities to diagnose and counsel are even scarce. Educating the public about this disease and creating appropriate support systems is an urgent need of the hour, she adds.

According to the Bangalore Chapter of the Alzheimer's Society of India, over 32,000 people in the city suffer from Alzheimer's or dementia-related disorders. September 21 is observed as World Alzheimer's Day and the theme for this year is 'Remember Me'.

AFSHAN YASMEEN

DECCAN HERALD • TUESDAY, SEPTEMBER 22, 2015

### Memory clinics need of the hour, say experts

#### Dearth in professional care for Alzheimer's and dementia in Bengaluru

Reshma Ravishanker

BENGALURU: If financial constraints is one of the main factors contributing to the inefficient management of Alzheimer's disease, minimal access to professional assistance is another.

Cases of Alzheimer's and in turn dementia are in growing numbers. For a City that has a large number of old-age homes, those offering professional care for dementia patients are a few.

Ritu (name changed) whose father suffers from Alzheimer's speaks about the challenges they had to face to get medical care for him.

Ritu had to move to New Delhi recently. However, having no choice, she had to leave her father who is a senior citizen behind at Nightingales Medical Trust in Bengaluru. The reason being, the fewer options to get professional help in New Delhi.

"Most day-care centres do not have trained hands to deal with patients who have Alzheimer's. We found several day-care homes in Bengaluru. Most of them, however, said they did not have professionals who could take care of senior citizens with dementia. To look out for a place is itself a tedious task," she said and added, "Even as there are several caregivers, not many are trained to handle Alzheimer's."

Ask mental health professionals in the City and they say that not more than five centres in Bengaluru have a full fledged clinic to manage dementia patients.

Speaking to *Deccan Herald*, Dr Radha S Murthy, president, Alzheimer's and Related Disorders Society of India - Bengaluru Chapter, said to set up memory clinics is the need of the hour.

"For someone with behavioural disorders, who is unable to do their day-to-day activities or to help active aging, a memory clinic is necessary. Cognitive stimulation is necessary to facilitate this and effective management can lower the risk factors," said Dr Radha.

Nidhi Dev, neuropsychologist, Cognitive Neurology Clinic said recent studies indicate that dementia cases are expected to double by 2030. "Care is based on individual needs and rate of deterioration. Sometimes, the caregivers themselves are stressed. It is essential to have support groups," she added.

Dev also suggests that anyone getting into an old-age home ought to be screened for symptoms of dementia and ideally, the screening has to be repeated once every six months.

DH News Service

### SUPPORT GROUP MEETINGS: PRESS NOTE

Caregivers to meet on Feb 27

Nightingales Centre for Ageing and Alzheimer's and the Alzheimer's and Related Disorders Society of India have jointly organised a meeting of the support group of caregivers for persons with dementia. The meeting will be held on February 27 at Nightingales Elders' Enrichment Centre, 148, 11th Main, between 16th and 17th cross, Malleswaram at 2.30 pm.

Uma Trasi, dietician from Manipal Hospital, will speak on "Young at Heart: Healthy aging is a life-long approach" with specific focus on diet in dementia. For details, contact: 92437 37342, 080 2334 2929.

Workshop for caretakers

The Alzheimer's and Related Disorders Society of India (ARDSI), Bangalore Chapter, Nightingales Centre for Ageing and Alzheimer's will hold a support group meeting for caretakers of persons with Dementia on November 28. The meeting will be held at Nightingales Trust Bagechi Centre for Active Ageing, 922, 22nd Main, 9th Cross, JP Nagar II Phase between 2.15 - 4.30 pm.

For more details, call 9243737342/080 69989775, according to an official press release.

**Challenges:**

- Lack of awareness amongst the public and dementia caregiving community regarding the professional support available , stigma about the concept of dementia day care, residential care for people with dementia
- Difficulties in getting new members, as most of them ask for the benefits they can receive as a member.
- Lack of interest in participating in support group meetings inspite of personal invitations/emails and reminders.

**Future plans:**

Our aim is to reach out to more people with dementia and the caregivers through various initiatives. With the launch of the subsidized dementia care program, our aim to assist more elders in need of care and support across geographical locations.

We plan to reach out to various senior citizens forums, police personnel's, auto drivers etc. to bring in awareness about the concept of healthy ageing and dementia.

To involve more family carers and persons with dementia in our activities.

To observe World Alzheimer's day 2016 in a meaningful way.

To target 50 new life members for the year 2016-17.

**Conclusion:**

The year has been an extension of efforts to reach out to more people and raise awareness about healthy ageing and services of our Chapter. We are grateful to all our committee members and family carers who have proactively helped our Chapter to spread its wings to support people with dementia and their carers. A warm welcome to all our new members and we look forward to working together to make Bangalore a dementia friendly city.

\*\*\*\*\*